DOCUMENT RESUME

ED 386 000 EC 304 202

AUTHOR Weston, Marsha C.
TITLE What about Me?: A Practicum Addressing the Needs of Children Who Have a Preschool Sibling with Impaired Hearing.
PUB DATE 29 May 95
NOTE 56p.; Ed.D. Practicum, Nova Southeastern University.
PUB TYPE Dissertations/Theses - Practicum Papers (043) -- Tests/Evaluation Instruments (160)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Clinics; Community Programs; *Correspondence Study; Elementary Education; Elementary School Students; Emotional Adjustment; *Family Involvement; *Hearing Impairments; Information Needs; Intervention; *Material Development; Preschool Children; Preschool Education; *Reading Materials; Sibling Relationship; *Siblings; Symptoms (Individual Disorders)

ABSTRACT

This practicum developed a special program to serve the elementary school child who has a preschool sibling with a hearing impairment. A special book addressing the cognitive and emotional needs of the siblings was written and distributed to 35 children whose families were enrolled in a clinic-sponsored correspondence program and to 15 children whose families participated in on-site clinic programming for preschool children, ages 2-5, with hearing impairments. The book provides information about the anatomy of the ear, hearing loss, assistive devices, communication, and methods of teaching children who have impaired hearing. Feelings which may be experienced by children whose sibling is hearing impaired are described. Games and illustrations are included in the book; additional children's reading materials are identified. A mail-in card allows the child to write to the clinic with questions or concerns. Questionnaires about the book were returned by 12 children and 6 parents from the correspondence group and by 8 children and 7 parents from the on-site group. Based on positive responses, the book is being used on-site and through distance education to include all family members in programming. The child and parent questionnaires are appended. (Contains 27 references.) (SW)

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What About Me?: A Practicum Addressing the Needs of Children Who Have a Preschool Sibling with Impaired Hearing

by

Marsha C. Weston

Cluster 55

A Practicum II Report Presented to the
Ed.D. Program in Child and Youth Studies
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Education

NOVA SOUTHEASTERN UNIVERSITY
1995

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PRACTICUM APPROVAL SHEET

This practicum took place as described.

Verifier: Sandra Meyer

Sandra Meyer, Ed.D.

Director, Correspondence Education

Los Angeles, California

May 12, 1995
Date

This practicum report was submitted by Marsha C. Weston under the direction of the adviser listed below. It was submitted to the Ed.D. Program in Child and Youth Studies and approved in partial fulfillment of the requirements for the degree of Doctor of Education at Nova Southeastern University.

Approved:

May 29 1995
Date of Final Approval of Report

Mary Staggs Ed.D.
Mary Staggs, Ed.D., Adviser

Acknowledgments

To my precious parents, Mary and Tilden Corenblum, for their gifts of life, love, and my very special siblings.

To my siblings, Ilene and Stuart, with gratitude, admiration, and love.

Alan - to old age, grapefruit, and palm trees!

To Shayne, Marni, and Scott, a special part of my heart and soul.

A rose is a rose is a rose, but there is only one "Rose Bud."

Thank you, Sandy, not just for being "the esteemed," but for being a good teacher, mentor, and dear friend.

To my co-workers and all the very special families of young hearing impaired children - thank you for your "hope, guidance, and encouragement."

A special thank you to a very special adviser, Mary Staggs.

Last, but not least, D.K., "yea!"

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ABSTRACT

What About Me?: A Practicum Addressing the Needs of Children Who Have a Preschool Sibling with Impaired Hearing. Weston, Marsha C., 1995. Siblings/Deaf Children/Sibling Programs/Special Needs Families.

This practicum was designed to create a program which would meet the unique and special needs of school age children who have a preschool age brother or sister with impaired hearing. A special book which addressed the cognitive and emotional needs of these children was created and distributed to children whose families participate in programs offered by a private not-for-profit organization serving families of infant and preschool hearing impaired children.

Each child who received the book and his or her parent(s) were asked to complete a questionnaire. An envelope was provided for the return of the questionnaires. In addition to responding to the questions on the questionnaire, participants were encouraged to share concerns, comments, questions, and suggestions.

As a result of the positive response to the special program, it is now being included in services offered by the organization. The book will be used in both on-site and distance education programs and serves as a vehicle for including all family members in programming.

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May 26, 1995 Marsha Weston

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CHAPTER I

INTRODUCTION

Description of Community

The community in which this writer works is a large metropolitan area in the western United States. It is served by all major forms of transportation and has several airports, bus and train stations. The geography, industries and population are extremely diverse.

In the area, there are deserts, mountains, lakes and an ocean. Consequently, there are also living facilities which include high rise apartments, smaller multi-family housing units, single family homes, and beach and vacation condominiums and cottages. A wide range of recreation and leisure activities can be enjoyed by the residents of the community and those visiting the area. This includes recreational and professional sports, museums, amusement parks, shopping, fine and casual dining, and a wide range of cultural activities.

As would be expected in a large urban area with diverse geography, there are equally diverse industries. Some of these are: tourism, entertainment, petroleum, aerospace, computer companies, and universities. All of these industries are interspersed throughout the geographic area.

People living in this area are from many different ethnic backgrounds. Many languages are spoken in addition to English. These languages can be heard in schools, homes, the marketplace, and in every conceivable walk of life. While some people rush to become a part of the American culture and learn the English language, others work to preserve their native language and culture. The influence of this ethnic diversity can be seen throughout the community. Its influence can be felt in places such as schools, businesses, and the arts.

Writer's Work Setting and Role

This writer's work site is in the heart of this urban community, in an area that is as diverse as the population described. An example of this diversity can be seen by merely walking down streets of the neighborhood. One will see students going to classes at a major university or a small private parochial college, business people, and people on their way to one of the free medical clinics or social service agencies. These people will not only represent diverse educational and socioeconomic backgrounds, but they will also be heard to speak languages other than English.

The work site itself is a clinic which for over fifty years has provided service as well as hope, guidance, and encouragement to families of infant and preschool hearing impaired children from birth through age five. These families come from throughout the world. All services of the clinic, a private not-for-profit organization, focus on the family and are provided to them free of charge.

There are a variety of services offered through the clinic. One unique program is in conjunction with a major university. In this program,

graduate students are educated and trained to be eligible to receive master degree credentials in deaf education.

The on-site clinic programs include nursery school, demonstration home programs, Friday family program, audiological evaluations, summer sessions, and family education and support. Families who have hearing impaired children between the ages of two and six are eligible to participate in the nursery school program. The children are in class for one half day four days a week. The children in the older nursery school program and their teachers spend some afternoons in a nursery school with children who have normal hearing. The parents are actively involved in the nursery school program and also participate twice a month in parent classes, taught by teachers from the nursery school, and support groups, led by one of the two staff psychologists. Occasionally, there will be guest speakers.

The demonstration home programs serve families whose children are newly identified or are under two years of age. In a home like setting, they work with a teacher in order to learn how to make daily routine and play with their child a language learning opportunity. The parents also join other clinic parents twice a month in the classes and support groups. In addition, these families participate in a program on Fridays which includes additional classes and support while the children and any siblings are in a nursery school and day care setting.

While participating in clinic programs, children routinely have their hearing and amplification systems evaluated by the pediatric audiologist.

Any member of the community or visitor to the area can make an appointment for the audiologist to evaluate the hearing of a child who is under the age of six.

The summer session program is run much like the nursery school program. Families from all over the world come to the clinic for three weeks. During the three weeks, the children participate in the nursery school, work with individual tutors, have their hearing and amplification systems evaluated, and have developmental evaluations. Parents spend some time in the nursery school each morning before beginning their own classes and support groups. Siblings of the hearing impaired children who are between the ages of 6 and 12 also have a special sibling group during the summer session. This program includes some traditional day camp activities, education about hearing loss and communication, and a support group.

The other area of service provided by the clinic, and the one in which this work will focus, is distance education. At the conclusion of 1994, the correspondence education department had served over 70,000 families from throughout the world. Approximately 3,000 families receive services from this department during the course of each year.

A variety of lessons in either English or Spanish are available to families. For families whose children are younger than 18 months, there is a baby course which consists of 10 lessons. Families whose children are 18 months through age 5, use the preschool course which consists of 12 lessons. There is also a 12 lesson program with accompanying learning steps for families of children who are both visually and hearing impaired.

Parents receive the program materials one lesson at a time. The families using the preschool course also receive a series of four video tapes if they are in the United States or a country using the National Television Standards Conventions (NTSC) system.

The lessons are divided into specific sections which are presented developmentally and sequentially. The paper of each section is a different color. The first part of each lesson is about child development. This is followed by a communication section which gives information about language development, audiology, amplification, and development of communication skills. The activity section of each lesson includes games and activities designed for facilitating skills in areas such as speech, listening, everyday activities, thinking, and play. The final section of each lesson contains a resource section of organizations and publications should parents wish further information or additional help.

A series of special topic papers in areas such as toilet training, discipline and hearing aid use are also available. All families receive the papers about hearing aids and hearing tests, and families in the United States also receive a paper about children's rights under the public laws. The other papers are sent when they have been requested or when it is felt that they would be helpful to the family.

There is a toll free telephone line available to professionals and families in the United States. The line may be used for inquiries, enrollments, referrals, general help, support, and reporting on lesson materials. A resource file is maintained in the department's computer in order to have continually updated and easily accessible information for use in the department and for sharing with families and professionals.

The department has its own print shop. All lessons and other materials are printed in the print shop as well as some of the materials for the on-site programs.

The department is composed of a director and staff members whose responsibilities include activities allowing for the successful fulfillment of its missions as previously stated and the philosophies of the clinic. This includes the following concepts: (a) Parents are their children's most important and most effective teachers; (b) early identification, early intervention, and early amplification are necessities for children who have impaired hearing; and (c) parents deserve and are entitled to hope, guidance and encouragement toward the fulfillment of their family's maximum potential.

This writer is a parent educator in the correspondence department and is responsible for replying to letters, applications and inquiries from families. This writer also has the main but not sole responsibility of: (a) responding to incoming calls on the toll free line from families and professionals and (b) keeping the computer resource file up to date.

All of the parent educators are encouraged through a variety of ways to remain current in the subjects of early childhood intervention and education, deaf education, audiology and related technology. This may be done through activities which include but are not limited to participation in conferences and workshops, in-service programs, and sharing of articles and other print items.

Parent educators also make presentations at conferences, seminars, and conventions in several roles. For example, the parent educator may be

telling others about the various programs sponsored by the clinic. Or, the parent educator may be making a presentation or leading a discussion at a conference, convention or meeting. During the past several years, parent educators have presented one week seminars in Mexico for families of hearing impaired children and professionals who may work with these families or be interested in expanding their own expertise in the area of early intervention and education for hearing impaired infants and preschoolers. This writer has had the opportunity to participate in all of these activities.

CHAPTER II

STUDY OF THE PROBLEM

Problem Description

Elementary school age siblings of hearing impaired preschool children have unique and special needs that deserve attention. One of the missions of the clinic is to serve the entire family, yet the unique and special needs of siblings had not been thoroughly addressed. Materials were needed which were age and developmentally appropriate. Although there are sibling newsletters available, they did not address specific disabilities. Current legislation in the United States supports the notion that each member of the family deserves service and is entitled to it (Rothstein, 1990).

Problem Documentation

Correspondence from families and professionals, interviews with siblings of hearing impaired children, and the emergence of newsletters and programs for siblings of special needs children substantiated the existence of the problem. Parents using the correspondence lessons had expressed concerns about their children who have normal hearing. They frequently asked how they might include their child with normal hearing as

they used the correspondence materials as they did not want the child with normal hearing to feel excluded. Parents also expressed concern about giving enough individual time to the child who had normal hearing.

Professionals working with families of hearing impaired children have also experienced a void in the area of siblings. They had contacted the department to learn whether or not the correspondence education department had suggestions or programs for siblings that they might use for populations with whom they were working.

Interviews with school age siblings participating in an on-site program for siblings of hearing impaired children further substantiated the need for a special program. Not only did the children express a desire for a special program, but they also had ideas about the types of materials they would like the program to include.

Recent newsletters such as those published by The Sibling Information Network and Sibling Forum support the notion that the siblings of special needs children have unique and special needs of their own. The children who share their letters and poems express the need to have a variety of concerns and feelings met.

Causative Analysis

There were several causes to the problem of addressing the unique and special needs of normally hearing siblings of preschool hearing impaired children. That these children have unique and special needs is being addressed more and more in the literature and by parents. Previously, attention has been focused on the child with the disability.

Including information in the lesson materials for parents to use with siblings did not totally address the needs and concerns of parents or

siblings. As more and more attention was given to each member of the family, then the areas which were deficient become more apparent.

Even when a need for service is thought to exist, it takes time to verify the need and create the materials. It is also important that services not be duplicated. Therefore, it was important to learn about existing programs which may have been serving this population.

Relationship of the Problem to the Literature

There is a growing body of literature which is related to siblings of children with special needs. The literature regarding siblings of children with impaired hearing, while growing, is much more limited. Some of the literature addresses the entire family of the child who has special needs. Perhaps this is, in part, related to some of the public laws which include families in the plan of intervention for the child (Rothstein, 1990) and the increased focus on involving the whole family in programs for children with disabilities (Summers, Bridge, & Summers, 1991).

Several books for children who have siblings with impaired hearing have been written. One of these, "Is It Catching?" A Book for Children with Hearing-Impaired Sisters or Brothers, describes some of the feelings hearing children experience and also gives some information about impaired hearing and amplification (Hall, 1982). Very simple black and white drawings help make this book easy to read and enjoy. According to the author, the book is meant to be a starting point for parents or teachers and siblings of hearing impaired children to use together and was created as a result of one teacher's experiences with families in a homebound program.

Some books attempt to portray what hearing impairment is like or how it feels to have a sibling who is hearing impaired. For example, in My Sister's Silent World, an older sibling discusses life with her hearing impaired sister (Arthur, 1979). In the book, I Have a Sister-My Sister Is Deaf, a hearing sibling describes the ways in which her hearing impaired sibling experiences everyday situations (Peterson, 1977).

There are also several newsletters which address siblings of special needs children. The Sibling Information Network, For Siblings Only, Sibling Forum, and SibFACTS provide a place for the siblings of special needs children to learn that there are other children sharing the same kinds of feeling they have as a result of a special child living in the family. These newsletters do not focus on specific disabilities but address the general needs and concerns of siblings of children with special needs. Some of them are for children of specific ages and others can be shared by the parents and the children. In all of the newsletters, children are invited to send in their letters, poems, and comments to share with other readers.

An actual program, Sibshops, has been created which provides a format for professionals to use in creating programs which address the needs of siblings of special needs children (Meyer, Vadasy, & Fewell, 1985b). Sibshops addresses the unique needs and concerns created by a special child's presence in the family and offers information for professionals and parents to use in creating meaningful activities for the siblings of the special needs child. And, the book, Living with a Brother or Sister with Special Needs: A Book for Sibs, not only describes a variety of handicaps and the impact of the handicaps on individuals, but

also describes feelings which may be experienced by the non-handicapped brothers and sisters (Meyer, Vadasy & Fewell, 1985a).

Books for families may deal about feelings experienced by specific family members or actually provide suggested activities. Featherstone (1981) discusses the variety of feelings experienced by the different members in the family when there is a child who has special needs, the impact a disabled child's presence can have on a marriage, how help can be sought, and the impact on the lives of the siblings.

An example of activities for siblings and a format for their implementation is provided in a book by Lobato (1990). This book also provides parents with information about a variety of handicaps as well as the impact the handicaps may have on the "normal" sibling.

The similarities of siblings who have special needs and the strategies which can be used to help these children are addressed by Powell and Ogle (1985). Also addressed are the varying needs and feelings these children have in various environments such as home, school, and play.

Children who have a hearing impaired sibling have much in common with other children who have a brother or sister with special needs. They also have some unique and special needs. The parents of hearing impaired children recognize that the presence of a hearing impaired child in the family can have a unique and specific impact on each and every member of the family, including the hearing sibling (Atkins, 1987; Luterman, 1987; Malcolm, 1990; Murphy, 1979).

In addition to books, newsletters, and programs which address the siblings of special needs children, so has research addressed the population of siblings of children who have impaired hearing. Israelite's study (1986) comparing the self concept of siblings of hearing impaired children to the self concept of siblings of hearing children did not find significant differences in self concept, although siblings of hearing impaired children did include in their definition of self that they were the sibling of a special child. In another study comparing siblings of hearing impaired children with siblings of children without impaired hearing, Schwirian (1976) found little difference in self concept scores except in the areas of responsibility and social activity. In these areas, the siblings of hearing impaired children scored higher in areas of responsibility and had less time for social activity.

Studies of siblings of children with siblings who have a variety of special needs also show differences, but they, too, are not significant. The difference found, for example, by Dyson and Fewell (1989) was that the siblings who had a special needs brother or sister had higher self-concept scores.

Both the research studies and the literature discuss the specific problems and concerns of siblings of special needs children. These problems and concerns fall into specific categories. Quite often the concerns expressed by children who have siblings with special needs stem from their ignorance about the problem (Hall, 1982; Itzkowitz, 1990; Jabs, 1992; Klein & Schleifer, 1993; Lobato, 1990; Meyer et al., 1985a; Powell & Ogle, 1985). These children also experience a wide range of emotions

which include embarrassment, protectiveness, anger, fear, guilt, and sympathy (Featherstone, 1981; Itzkowitz, 1990; Jabs, 1992; Staff, 1991). Siblings who have brothers and sisters with special needs should have opportunities to express their emotions as well as to learn about the specific disabilities through a variety of interventions (Jabs, 1992; Lobato, 1990; Powell & Ogle, 1985). Siblings of children with special needs may, in fact, have special needs of their own which merit attention (Klein & Schleifer, 1993; Malcolm, 1990; Powell & Ogle, 1985).

Children who have siblings that are hearing impaired experience specific problems related to hearing impairment in addition to feelings and problems experienced by siblings of special needs children (Atkins, 1987; Lexington, 1974; Luetke-Stahlman, 1992; Luterman, 1987; Malcolm, 1990; Murphy, 1979). They may wonder what it is like to be hearing impaired and experiment with ways of blocking sound from their ears; they may have to learn another language, sign language, in order to communicate; they need to know about a variety of assistive devices from hearing aids to telecommunications; they worry about losing hearing; and they wonder if their own children will have impaired hearing.

The literature reviewed supports the notion that children who have a brother or sister who has special needs will in turn have unique and special needs. While there is great commonality amongst these children, there are also some specific areas worthy of attention for children who have a sister or brother with impaired hearing. The areas touched upon in the literature deal with psychology, health, cognitive information, and related fields.

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

The goal of this practicum was: school age siblings of hearing impaired children whose families are enrolled in the correspondence program of a private not-for-profit clinic will receive cognitive and emotional support. These children have unique and specific needs related to knowledge about hearing, hearing loss, communication, and habilitation. In addition, they experience specific emotions as a result of being a member of a family in which there is a child who has impaired hearing.

Expected Outcomes

School age children who have a preschool hearing impaired sibling and whose families are enrolled in either the correspondence education program or the on-site programs of a private not-for-profit clinic will be the recipients of a special program. Information in the program will give attention to areas of concern addressed in the literature, by families, and by professionals.

1. The school age siblings of hearing impaired preschool children will receive information about: the anatomy of the ear, hearing, hearing loss, causes of hearing loss, and technology for the amelioration of hearing loss.

2. The school age siblings of hearing impaired preschool children will receive information about: communication, methods of communication, and ways to enhance communication.

3. The school age siblings of hearing impaired preschool children will receive information about: feelings experienced by children who have a sibling with impaired hearing, ways to handle feelings, and questions that are common amongst children who have a sibling with impaired hearing.

4. The school age siblings of hearing impaired preschool children will receive information about: other resources and newsletters.

5. The school age siblings of hearing impaired preschool children will have a nonjudgmental place to send a letter in order to express concerns, feelings, and/or questions.

Measurement of Outcomes

The outcomes were measured by questionnaires and the responses received from professionals involved with on-site services. The questionnaires provided the children with the opportunity to indicate if they: looked at the book; tried any of the activities; received cognitive information; had feelings explained; and/or had additional questions, concerns, or thoughts. These responses are specifically related to the information presented in the program in the areas of hearing, communication, feelings, and resources.

To ensure receipt of responses, the special correspondence program for school age siblings was distributed to both on-site and correspondence families. A letter of explanation (Appendix A) was given to parents of the children in the on-site programs since some of them may have been unfamiliar with programming provided by the distance education department. Separate questionnaires (Appendices B and C) were created and dispersed along with an addressed envelope to both the siblings and the parents in each family that had received one of the special correspondence program booklets.

There were additional indicators of the success of the project. They included the spontaneous responses of the siblings, active use of the material, requests and referrals for additional distribution of the book, responses from parents, and comments from the on-site personnel.

CHAPTER IV

SOLUTION STRATEGY

Being the sibling of a preschool hearing impaired child creates unique and special needs. The creation and distribution of a special correspondence program for school age siblings of preschool hearing impaired children is one method of addressing these unique and special needs.

Discussion and Evaluation of Solutions

The literature supports the premise that siblings of young hearing impaired children have unique and special needs. The literature is also supportive of the concepts of providing specific programming and services to address these needs. The identification of these special needs coupled with an emphasis of involving the whole family in programs for children with special needs further supports the notion of providing service to these siblings (Summers, Bridge, & Summers, 1991).

There is a growing body of literature focusing on children who have siblings with special needs. Discussion includes the needs of these children as well as some specific program ideas. Itzkowitz and Bohorquez (1986) give a specific nine step program for creating a program for

siblings of special needs children which can be adapted to a specific or mixed group of children. The program guidelines address what will be included in the program and the manner in which it will be run as well as logistics such as cost, advertising and evaluation.

In The Sibling Manual edited by Morgan (1992), step by step procedures for setting up all facets of a program for siblings of special children are presented. The program is presented in a notebook with color coded paper for the specific sections.

The program for siblings which was written by Levine (1990) addresses program planning for siblings in two age groups, 4 to 9 and 10 to teen. The separation into these two age groups is related to the focus of their concerns. Younger children are more concerned with sharing the attention of their parents, and older children are more concerned with the reactions of their peers to the child in the family who has special needs. The activities are divided into five specific areas. They include other resources, specific things to do, and related discussion.

Meyer, Vadasy, and Fewell (1985b) created a program for siblings which includes specific activities designed for accomplishing specific goals which in turn will meet the needs of the siblings of special children. A unique feature of this program is a discussion of activities for parents. In these activities, parents have the opportunity to learn about some of the concerns their "normal" children may have as a result of being the sibling of a special child.

Summers, Bridge, and Summers (1991) suggest a six session sibling support group. These sessions would progress from familiarizing activities

to those which are more specific in nature. The more specific activities include learning what it is like to have a disability, discussing feelings about having a special sibling, and actually having the opportunity to observe the school activities of a special sibling.

In addition to these specific programs, there is information in some books that can be used for creating programs and addressing the concerns and needs of siblings of special needs children (Lobato, 1990; Powell & Ogle, 1985). These programs, like the ones described in the preceding discussion, have specific goals and objectives which are presented in a progressive format. Some of the sample activities which are presented give the reader ideas which can be used in leading discussion groups and preparing programming.

A review of the literature provided ideas as well as concerns to address and information to include in creation of a correspondence program for school age siblings of hearing impaired preschool children. While there are some things which are common amongst all children who have siblings with special needs, there are also some concerns specific to those who have hearing impaired siblings (Atkins, 1987; Lexington School for the Deaf, 1974; Luterman, 1987; Murphy, 1979).

Siblings of hearing impaired children need to have specific cognitive information. In the correspondence program, is information about the anatomy of the ear, how people ear, and some things known to cause hearing loss. Information about the assistive devices used to ameliorate the impact of hearing loss and the importance of early intervention for

hearing impaired children is also provided. The other cognitive areas addressed focus on communication techniques and methodologies used for teaching children who have impaired hearing.

The emotional needs of these children has also been addressed. They need to know, and will find, that they are not alone in their situation or in the feelings they experience, that there is a vehicle for the expression of their feelings and concerns, and that these feelings and concerns will be addressed in a confidential and nonjudgmental manner.

Information is at a level which is appropriate for the majority of children in this fairly wide age group. In addition, other resources for those who may wish to expand upon the information presented to them is provided.

Siblings of hearing impaired children can also benefit from knowing about activities in which they can participate which will help them understand the experiences of those who have impaired hearing. Particularly helpful are activities that will familiarize these children with programming and ways of being involved in programs similar to those in which their hearing impaired siblings participate (Malcolm, 1990). This, too, is a part of the correspondence program.

Description of Selected Solution

School age siblings of hearing impaired preschool children have unique and special needs. Because of the importance of addressing these needs, this writer created a book to be used as a correspondence program for these children. The book offers cognitive information and emotional

support through an interactive format. With the consent of the director of the correspondence education department, the writer distributed the book to families and children involved in both on-site and distance education programs.

Report of Action Taken

Implementation of this project took place over a period of eight months. Following a specific time table, allowed for the creation, dissemination, and evaluation of a correspondence program for school age siblings of preschool hearing impaired children.

During the first month, the writer worked closely with the director of the correspondence education department to create and design the format for the correspondence program for siblings. This included making decisions about the length of the book, designing a format for the book which would be complementary to materials being disseminated by the department, and creating guidelines for responding to any responses received from children who had been sent the book. Another part of these meetings included the formalizing of the writer's responsibilities for printing and disseminating the book.

Once the basic format for the book had been established, an outline for writing the book was created. This was followed by the gathering of specific, age appropriate materials which the literature reviewed suggested would be important cognitive and affective information for school age children who had a preschool sibling with impaired hearing.

Information to be included in the book came from two other sources as well. In anticipation of this project, the writer interviewed two groups

of children who participated in the sibling program which is one of the components of the three week international summer sessions held each year. These children had very specific thoughts about the creation of a correspondence book. In addition to commenting that they thought it was a good idea, they suggested it have a map so children could know where the clinic was located and things they could do. They did not want a book just to read. Their suggestions were honored, and the book has a map, numerous diagrams and drawings, and some interactive activity on each page.

The two staff members who are responsible for the on-site summer sibling programs also provided valuable information with regard to the cognitive and affective activities and materials they used. In addition to sharing ideas and experiences, they also shared their outlines and resource materials with the writer.

Another activity that took place during the first month was the contacting of the illustrator of the current correspondence program in order to learn if she would be interested in working on this project. Estimated costs and the amount of time she would need for completing the illustrations were discussed.

During the second, third, and fourth months the correspondence program for siblings of preschool children who have impaired hearing was written. The writing took into consideration (a) the format of the lessons received by parents using the correspondence education programs, presenting materials in a developmental format and on different colored sheets of paper for different topics; (b) the discussions which had been

held with the department chairperson; (c) the information gathered through research and the materials received from providers of on-site services, explaining about the ear, causes of hearing loss, amplification, assistive devices, communication, techniques for communicating, methodologies used to teach those with impaired hearing, discussions of feelings in general and specifically as they relate to having a sibling with impaired hearing in the family; and (d) the suggestions which had been made by children participating in an on-site sibling program as part of their family's participation in one of two three week summer programs, a map, games, and interactive opportunities.

As sections were completed, they were saved on the hard drives of the computer in the clinic as well as the one in the writer's home. They were also saved on a disc which allowed for work to take place on this project in two different locations. In addition to facilitating the writing of the program, having the program in the computer allows for the information to be available for future updating and revising should it be needed.

Four major activities took place during the fifth month. The first of these activities, proofreading, was done by this writer and the director of the correspondence education department. Attention was given to format, typographical errors, appropriateness of language for the target population, and compatibility with other departmental materials. As a result of these proofreading activities, the two staff psychologists were asked to read the book with special attention to the affective areas. As a result of feedback from the psychologists, some changes were made in that section of the book.

Illustrations had to be inserted into the copy once the proofreading had taken place. Originally, it had been planned for the illustrator who had done the drawings for the correspondence lessons to do the drawings for the book. However, in going through the art work which was already available, the writer, with the consent of the director of the correspondence education department, decided to "cut and paste" based on the material on hand. In addition, one of the parent educators who has artistic abilities, volunteered to do some drawings when the material which was available was insufficient or inappropriate. Furthermore, since the book was just going to be used for a trial program, this proved to be a more economical means of including illustrations and drawings. After the illustrations had been put in place, the book was proofread again and necessary corrections were made.

Although the clinic has a print shop and most materials are printed in house, the decision was made to use a copy machine for the first printing of "What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing." This was done in the interest of economics since making plates and printing exact copy before receiving feedback on the book was deemed wasteful. However, the paper used for the copies was the same weight and style as that used for all other correspondence programs and special papers.

The fourth activity that took place during the fifth month was the creation of a list of children who would be the first recipients of the materials. This list was created through a search of the data base in the department and the solicitation of names from the faculty offering on-site

services. In order to enhance the probability of receiving responses from the initial users of the program, the data base search focused on children whose families reside in the United States or Canada and who had been active in their use of the correspondence course. Children who participated in a one day on-site sibling program also received the book.

During the sixth and seventh months, the new program for school age siblings of preschool hearing impaired children was distributed, 15 to children who had siblings in the on-site program and who participated in a one day program for siblings and 35 to children whose families were enrolled in the correspondence education program and whose sibling had no disability other than impaired hearing. All of the programs were addressed to both the parent and the child. The rationale for this was based on the premise that it is the parents who make contact with the clinic and decide to enroll the family in the programs whether they be on-site or through correspondence. A cover letter (Appendix A) was given to parents of children in the on-site program since they may not have known about the services provided by the correspondence education department. If there were more than one school age child in the family, each of them received their own copy of the program.

A questionnaire (Appendix B) for the children who received the program as part of the on-site sibling day was enclosed with the initial envelope. There was also a questionnaire for the parents (Appendix C). Families involved with on-site programs were asked to return the questionnaires approximately three weeks after they received the program.

An addressed envelope was provided for the child and the parent. Respondents did not have to sign their names.

Two weeks after the programs had been mailed to the families in the correspondence programs, they were mailed a questionnaire (Appendices B and C). Again, a requested response date and an envelope addressed to the clinic were included. During the latter half of the seventh month, a reminder for the siblings and parents who had received the questionnaires as part of the on-site sibling day was put into the lockers of the hearing impaired children involved in on-site programs.

At the conclusion of eight months, the new correspondence program for school age siblings of hearing impaired preschool children had been in use for at least a couple of months, and the first spontaneous responses from the children and some questionnaires had been received. The responses and any constructive criticisms have been incorporated into the final program. "What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing" is being printed in the print shop at the clinic.

CHAPTER V

RESULTS, DISCUSSION AND RECOMMENDATIONS

Elementary school age siblings of hearing impaired preschool children have unique and special needs that deserve attention. Although one of the missions of the private not-for-profit clinic is to serve the entire family, this particular group's needs had not been thoroughly addressed. There was a need for materials which were age and developmentally appropriate which would meet both the cognitive and affective needs of these children.

The solution strategy which was used was to create a correspondence program for school age siblings of preschool hearing impaired children. The program complements the correspondence lessons which are currently sent to families of hearing impaired preschool children both in style and manner of presentation. There is specific information about anatomy of the ear, hearing loss, assistive devices, communication, and methods of teaching children who have impaired hearing. A section about feelings not only describes feelings experienced by all children but also those that are specific to children who have a young brother or sister who has impaired hearing. The final section provides additional resources

should the children wish to read a little more about things presented in the book. Throughout the program, there are participatory opportunities in the forms of games, illustrations, writing thoughts, and drawing pictures. The final page of the book is a page for the children to write to the clinic to "talk," ask questions, or express concerns. The page can be folded and mailed since the address of the clinic is already imprinted on the reverse side of the paper.

Results

As a result of this practicum project, a program now exists which meets the unique and specific needs of school age children who have a preschool sibling who is hearing impaired. This program can be used as a correspondence lesson or in conjunction with other sibling programs. It can be used by the school age child, the child and a parent or other relative, or by the child and a teacher or other professional.

The writer worked closely with on-site personnel in devising a format and in discussing information to be included in the book. This was reinforced through reviews of literature and existing programs designed for children who have siblings with special needs and, specifically, siblings of children with impaired hearing.

The completed book was disbursed to families receiving services through either on-site programming or distance education. In all instances, the hearing impaired child had no other significant area of exceptionality. The hearing impaired children in the on-site program ranged in age from two through five and had hearing losses ranging from severe to profound. They were being educated using an auditory oral approach. The siblings

who received the book ranged in age from 6 to 15. While the book was created for children between the ages of 6 and 12, the decision was made to give a copy to the 15 year old since he participated in the on-site day for siblings.

When the book was mailed, the hearing impaired children whose school age siblings received the book through the correspondence education department ranged in age from seven months to five years and seven months. Their families used a variety of educational methodologies which included auditory oral, auditory verbal, cued speech, total communication, Signed Exact English, and American Sign Language. The hearing losses of the preschool hearing impaired child ranged from mild to moderate to profound. The siblings who received the book ranged in age from 6 years 2 months to 12 years. The initial mailing of the book was to families who resided in either the United States or Canada.

Both the child who received the book and his or her parent(s) received a questionnaire about the book (Appendices B and C). Fifteen books were distributed to families involved in on-site services. This represented 13 families since two of the hearing impaired children had more than one school age sibling. Of the 15 books distributed on-site, 8 children and 7 parents completed and returned the questionnaire. In addition, two children spontaneously completed and returned the final page in the book, the page designed for them to share concerns and comments.

Thirty five books were distributed to families in the correspondence program. This represented 25 families as 10 hearing impaired children

had more than one school age sibling. There were three school age children who received the book who had more than one hearing impaired sibling. Of these 35 books, 12 children and 6 parents completed and returned the questionnaire they had been sent. One child spontaneously returned the final page of the book sharing her comments and feelings about her hearing impaired sibling. The spontaneous letters all received a written response signed by the director of the correspondence education department.

Completed questionnaires were received from 20 children and 13 parents. Because responses to the questionnaires were anonymous, follow up letters could not be sent to nonrespondents. This was a choice the writer made which complements the privacy and "family driven" policies of the clinic. The responses from the children are presented in Table 1.

Table 1

Questionnaire Responses from Children

Question	Responses	
	Yes	No
1. Did you look at the booklet?	20	0
2. Did you try any of the activities?	19	1
3. Did the booklet answer some questions for you?	20	0
4. Did the booklet explain some feelings you have?	19	1
5. Do you think other boys and girls who have a sibling who has trouble hearing would like to get this booklet?	20	0

As can be seen, all of children who responded to the questionnaire reported that they had looked at the book, had questions answered, and thought other boys and girls who had a sibling with impaired hearing would like to get the book. Only one child did not try any of the activities. Although there were no suggestions about specific ideas for this book, two children suggested that a similar book should be created for teenagers.

All of the parents who responded to the questionnaire said they had read the book and thought the book would be helpful to other children who had a sibling with impaired hearing. Only one parent commented that his/her child had not read the book, and one parent wrote that he/she read the book to the child who had received the book.

Both parents and children were asked if there were someone else they thought should receive the book. The children did not supply any names. One child did add a postscript to the questionnaire. It said, "I want you to keep sending this booklet around! It helped me through questions like 'why' and 'how,' but thanks to you I got answers." Parents were specific in sharing names and ideas. The names they shared were both families and service providers.

When the parents and children elaborated on responses, their comments were quite similar with regard to the strengths and weaknesses of the book. The primary weakness cited was that children under the age of seven would benefit more from a smaller book which had less discussion and pictures with more simplicity.

The two areas of strength which were mentioned most often were the sections entitled "Why Can't My Sibling Hear?" and the questions and

answers in the section "How Are You Feeling? What Are You Thinking?" One family, in talking about these sections, said that these were areas "...we thought our son knew, but in reality he didn't have a thorough understanding." Positive comments were also received about the section describing how to communicate with a child who has impaired hearing.

In addition to discussing strengths and weaknesses there were two other suggestions from parents. One of these, a book for teens, was similar to comments received from two of the children. The other suggestion was that there be more specific information about the cochlear implant.

One family read the book closely enough to find two typographical errors and a sentence that left them feeling uncomfortable. The errors were fixed on the computer discs and the remaining copies of the book and the sentence in question was deleted.

Discussion

When there is a child in the family who has impaired hearing, each and every family member is affected (Atkins, 1987; Luterman, 1987; Malcolm, 1990; Murphy, 1979). Services for the child and the family are now available in a variety of arenas. And, in this country, there are laws mandating and describing services (National Association, 1994; Rothstein, 1990).

What about the school age sibling of the child who has impaired hearing? Until recently, little specific attention has been given to any children who have a sibling with special needs (Summers et al., 1991). As of 1987, only two known studies examining siblings of children with

impaired hearing had been published (Luterman, 1987). Children who have a sibling who has impaired hearing have unique and specific needs in areas which are both cognitive and affective (Atkins, 1987; Luetke-Stahlman, 1992; Luterman, 1987; Malcolm, 1990).

To provide a vehicle which would address some of the cognitive and affective needs of school age children who had a sibling with impaired hearing, a book was created and distributed. Each section of the book is on a different colored paper and the material in the sections is presented sequentially and developmentally. The cognitive section includes information about the ear and communication. The affective section includes information about feelings and expression of feelings as well as a section of questions and answers. On each page there is something for the child to do. It may be a word game, filling in a blank, answering a question, drawing a picture, or following the path of a sound wave from the air to the brain. Focusing on affective and cognitive information and varying the activities and the format, allows learning to take place in a "hands on" manner which has been found to be optimum for siblings of children with special needs (Atkins, 1987; Jabs, 1992; Levine, 1990; Lobato, 1990; Malcolm, 1990; Meyer et al., 1985b; Powell & Ogle, 1985; Summers et al., 1991).

The questionnaires which were returned indicate that the book met the goals of providing information and support to the children who received it. That it has the potential to be a viable tool for children who have a preschool sibling with impaired hearing is reflected in the

comments and letters received from parents and children and the recommendations made by parents regarding other individuals who should receive the book.

On-site personnel who read the book also expressed an interest in incorporating it into services offered to siblings who participate in the one day a semester sibling program and the two three week international summer sessions. These staff members see the book as a complement to the programming being offered to these children. For the children attending one of the summer sessions, the book can serve as reinforcement and carry over from the on-site summer activities.

As a result of the responses to the book, the director of the correspondence education department has included "What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing" in the materials distributed and offered by the department. The initial distribution will be to families expressing concern about the siblings of their hearing impaired child and for the children participating in the two 1995 three week summer sessions. As this report is being written, the book is being printed in the print shop at the clinic.

It was the goal of this practicum to meet the cognitive and emotional needs of school age children who have a preschool age sibling with impaired hearing. A book was created and distributed. The responses to the book indicate that the goal of providing a special tool for these school age children has been met. The distribution of the book by the correspondence education department of the clinic shows support for the book as one more way for the clinic to meet the needs of families of

children with impaired hearing and to continue its mission of offering hope, guidance, and encouragement to these families.

Recommendations

During the course of this project, several ideas arose which would be additional outcomes of this practicum. They are:

1. A separate book should be created for the hearing siblings who are between the ages of five and seven. The format should be like a "coloring book."

2. The new correspondence program for siblings should be translated into Spanish.

3. The discs created should be kept in a special place and updated as necessary. This will facilitate future reprints and rewrites.

4. Information about the book should be included with information packets detailing the services of the private not-for-profit clinic serving families of preschool hearing impaired children.

5. The on-site professionals working with siblings should have the book to use as a complement to their programs.

6. Consideration should be given to providing information about the book to organizations and newsletter publishers who address the needs of children who have siblings with special needs.

Dissemination

The first printing of "What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing" will consist of 100 books. Initial distribution will be to the children participating in the sibling program during one of the 1995 summer

sessions. It is the feeling of the staff involved with this program that the book will serve to reinforce the activities in which the children will be involved.

The book will also be mailed to people whose names were received when the questionnaires were returned by the families who received the first copies of the books. A cover letter will be created to accompany the books and to explain why they are being sent to the individuals receiving them. Families using the correspondence lessons who express particular concern about their hearing school age children will also receive the book.

Finally, as with the other materials of the private not-for-profit clinic serving families of young preschool hearing impaired children, the book will be available to professionals throughout the world at a price which will cover the cost of printing and shipping. It is expected that this availability will commence once costs and time lines for printing additional copies of the document have been established.

The creation and dissemination of this book is one more way in which this clinic will be able to address the needs of all members of the family. Its creation and dissemination provide one more avenue for the fulfillment of the mission of the clinic.

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APPENDIX A

PARENT LETTER

March 28, 1995

Dear Parent(s):

In an effort to serve all members of the family, the Correspondence Education Department has created the enclosed booklet, "What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing." We would like you, our "on site" families to have the first copies. This gives you a special opportunity to give us some important feedback.

Please share it with your hearing child(ren). The booklets are theirs to keep, write in, or use in any way they choose. We also encourage your child(ren) to use the final page of the booklet to share comments with us, ask questions, and even make suggestions about the booklet.

We want your feedback. Can we hear from you by Monday, April 24th? For your convenience, a questionnaire is enclosed. The thoughts and ideas of your child(ren) are also very important. Another questionnaire is enclosed for that purpose. A self-addressed envelope is enclosed for your convenience, or you may drop it off at the reception desk when you return to school on Monday, April 24th.

We hope your children and you enjoy this special book for siblings, and thank you for your comments and suggestions.

Sincerely,

Enc: Booklet
Evaluation (Parents)
Evaluation (Boys and Girls)

APPENDIX B

QUESTIONNAIRE FOR CHILDREN

Hi!

A little while ago you received a special booklet, ***"What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing."*** We hope you read and used the booklet. We hope you enjoyed it. Please take a few minutes to answer some questions, - even if you didn't finish reading it. What you think matters to us. Put your answers in the envelope with this letter. You can sign your name if you want to.

1. Did you look at the booklet? Yes_____ No_____

2. Did you try any of the activities? Yes_____ No____

3. Did the booklet answer some questions for you? Yes____ No_____

4. Did the booklet explain some feelings you have? Yes_____ No____

5. Do you think other boys and girls who have a sibling who has trouble hearing would like to get this booklet? Yes_____ No_____

6. Do you have some more questions or concerns?_____

_____

7. Do you have any ideas about something else that should be in the booklet?

_____

8. How old are you?_____

9. Are you a boy____ or a girl____?

Thank you for answering these questions!!! Please mail this by April 26, 1995!!!

Your friends at .....

Hi!

A little while ago you received a special booklet, ***"What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing."*** We hope you read and used the booklet. We hope you enjoyed it. Please take a few minutes to answer some questions. What you think matters to us. Put your answers in the envelope with this letter. You can sign your name if you want to.

1. Did you look at the booklet? Yes_____ No_____

2. Did you try any of the activities? Yes_____ No____

3. Did the booklet answer some questions for you? Yes____ No_____

4. Did the booklet explain some feelings you have? Yes_____ No____

5. Do you think other boys and girls who have a sibling who has trouble hearing would like to get this booklet? Yes_____ No_____

6. Do you have some more questions or concerns?_____

_____

7. Do you have any ideas about something else that should be in the booklet?

_____

Thank you for answering these questions!!!

Your friends at .....

APPENDIX C

QUESTIONNAIRE FOR PARENTS

Dear Parent(s):

Your family has received a new booklet designed for the siblings of your hearing impaired child(ren). We hope the booklet has been used by your school aged hearing child. Maybe it was also shared with you. Now we would appreciate your taking a few minutes to give us some reactions about the booklet, ***"What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing."***

1. Did you read the booklet? Yes____ No____

2. Did your school age hearing child read/use the booklet? Yes___ No____

3. Do you feel this booklet would be helpful to other siblings of hearing impaired children? Yes_____ No____

4. Please share one or two comments about the parts of the booklet that were most helpful. _____

_____

5. Please share one or two suggestions you may have that would improve the booklet._____

_____

6. Do you know a family that might want to receive this booklet?

_____

_____

_____

Thank you for taking the time to complete this questionnaire. Encourage your child to also complete and return the questionnaire he or she received. Please mail your response - even if you haven't finished with the booklet - by April, 26, 1995.

Sincerely,

Dear Parent(s):

Your family has received a new booklet designed for the siblings of your hearing impaired child(ren). We hope the booklet has been used by your school aged hearing child. Maybe it was also shared with you. Now we would appreciate your taking a few minutes to give us some reactions about the booklet, ***"What About Me?: A Special Book for Boys and Girls Who Have a Brother or Sister with Impaired Hearing."***

1. Did you read the booklet? Yes____ No____

2. Did your school age hearing child read/use the booklet? Yes___ No____

3. Do you feel this booklet would be helpful to other siblings of hearing impaired children? Yes_____ No____

4. Please share one or two comments about the parts of the booklet that were most helpful. _____

_____

5. Please share one or two suggestions you may have that would improve the booklet._____

_____

6. Do you know a family that might want to receive this booklet?

_____

_____

_____

Thank you for taking the time to complete this questionnaire. Please encourage your child to also complete and return the questionnaire he or she received.

Sincerely,